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The Importance of Medicaid for Children with Disabilities and Special Health Care Needs

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POLICY BRIEF: The Importance of Medicaid for Children with Disabilities and Special Health Care Needs

Produced by the 2017-2018 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees.

Executive Summary

Changes to Medicaid financing structure should be carefully considered because any change could have a potentially negative impact on children with disabilities and special health care needs (hereafter referred to as children with disabilities) and limit their access to critically needed health care services and community supports. Currently, Medicaid funding operates through a state and federal partnership, with the federal government providing 60% of funding on average. A cornerstone of Medicaid is the **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)** child health benefit. This program offers vital support services to children with disabilities, including early and periodic screenings, comprehensive wellness checks, and timely immunizations.

Historically, a majority of Americans have held a favorable view of the Medicaid program. Additionally, many individuals currently benefit from the program. In the state of Maine, 4 in 10 children benefit from Medicaid services – many of whom have disabilities. Since 1965, Medicaid has provided low or no-cost health care to low-income families of children with disabilities who would not otherwise be able to afford developmentally and medically necessary supports and services. Medicaid also fills insurance coverage gaps for privately insured, working families. Medicaid further allows many families the financial means to keep children with disabilities living at home, involved in their communities, and out of institutions (Musumeci & Foutz, 2018). This not only lifts a financial burden off families; states also see downstream economic benefits as services shift to more cost-effective community and home-based settings.

Policy Responses and Alternatives

Since 1980, many proposed changes have focused on limiting federal spending on Medicaid rather than improving services. For example, the two most common policy proposals are *block grants* and *per capita caps* which could help states reduce spending, but could also limit Medicaid's ability to adjust and meet the actual needs of recipients. These proposals could result in negative consequences, particularly for children with disabilities and their families (e.g., redefined eligibility criteria so that working families with children with disabilities lose access to health insurance, or limiting access to crucial medical and developmental services). Ultimately, changes focused solely on costs may reduce services and lead to greater health disparities among states.

Medicaid Waivers have provided states with an alternative to test new approaches that differ from federal program rules, potentially improving their programs and managing costs. An example of a waiver that has improved services for children with disabilities is the *Katie Beckett Waiver.* Implemented under the Reagan Administration in 1982, this program has served to make Medicaid more effective and efficient. Waivers, however, can also have negative consequences if they reduce eligibility or restrict access for children with disabilities and their families.

Stakeholders/Professional Opinions

Many stakeholders, pediatric health-related groups, and professionals from a variety of disciplines advocate for no major changes to Medicaid funding and eligibility structure in order to continue the vital access to health services that the program provides for children with disabilities. Professional organizations opposing major changes to Medicaid include the American Academy of Pediatrics, American Medical Association, National Association of Social Workers, American Occupational Therapy Association, American Speech-Language-Hearing Association, Academy of Nutrition and Dietetics, American College of Obstetricians and Gynecologists, and the Association of University Centers on Disabilities. Advocacy organizations opposing changes include the Kaiser Family Foundation, The ARC, March of Dimes, Families USA, Family Voices, the National Association of Councils on Developmental Disabilities, National Disability Rights Network, and the Autistic Self Advocacy Network.

Proposal

Any major change to Medicaid policy could have negative consequences for children with disabilities. Restructuring eligibility or financing for Medicaid would shift costs to states or families and likely result in funding cuts for this population. This would endanger benefits such as EPSDT or the *Katie Beckett Waiver* that are important to children with disabilities. The consequences of such a change could be devastating to families, burdening them with costs that could easily bankrupt even the most financially stable households. On a larger economic scale, services such as EPSDT improve quality of life for children with disabilities, enabling them to perform better academically, live in their communities, and ultimately become more productive, contributing members of society.

Our Medicaid program has been tested and refined over the past 50 years to provide the level of care necessary to properly serve children with disabilities. Block grants, per capita caps, and the use of waivers to reduce eligibility and benefits could threaten the system of comprehensive care built over these decades. While we recognize that there is not pending legislation addressing these issues, we encourage families, legislators, health-related professionals and advocacy organizations to remain vigilant to any proposed changes to the Medicaid program that could impact eligibility and access for children with disabilities and the community services they and their families need.

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